with patients' families as the state that is referred to is not one of qualified death. The patient should be described as having died, adding that some of the bodily organs are being supported mechanically in case they may be used for transplants. It is not appropriate to ask relatives for permission to disconnect support equipment in these cases. After death has occurred, that which used to be the body of the patient can be kept on organ support—not life support—until organs usable for transplant purposes are harvested or until it is established that consent to harvest the organs is not available.

The Decision to Withdraw Tube Feeding

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Physicians involved in the care of elderly patients are often faced with end-of-life decisions including withholding or withdrawal of tube feeding. More than 80% of deaths take place in the hospital or nursing home and the prolongation of life by medical technology has replaced natural processes.[1] We believe the availability of life-sustaining medical technology including tube feeding does not make physicians ethically obligated to use it once it is known that health and function cannot be restored and the burdens outweigh the benefits. Patients and their surrogate decision-makers have a right to refuse life-sustaining medical treatment they find burdensome. Tube feeding as a medical treatment, withholding of tube feeding as equivalent to withdrawal of tube feeding, the benefits versus the burdens of tube feeding, and the decision-making process involved in the withdrawal of medical treatment are considered Hawaii's statutes as they apply to decision-making and examples of cases to illustrate how these concepts are pertinent to patients whom we encounter in clinical practice are discussed.

Tube Feeding as a Medical Treatment

Some individuals view enteral feeding as basic supportive care that is ethically obligatory, and therefore, should not be withheld or withdrawn. The provision of food and water is believed to be symbolic of caring, comfort, and compassion.[3]

However, the majority ethical and legal position at this time is to regard enteral and parental nutrition and hydration as life-sustaining medical treatment with proportionate benefits and burdens that must be assessed individually from the perspective of the patient. As with all other forms of medical treatment, tube feeding can be refused or might not be appropriate. It is the obligation of the physician to obtain informed consent prior to the initiation of tube feeding. Over the last decade there have been numerous court cases supporting the right of the competent individual to refuse life-sustaining tube feeding and have expanded this legal concept to include incompetent individuals and individuals not imminently dying (patients who are in persistent vegetative states or who are very debilitated).[1-3] In 1990, Justice Sandra Day O'Connor, writing in a concurring opinion for the United States Supreme Court in the Cruzan case, stated unequivocally that artificial feeding should be considered a form of medical intervention.[4] Despite emerging legal consensus, in several states feeding tubes are explicitly excluded from the types of life-prolonging treatment that may be rejected in an advance directive such as a living will. Since July of 1991, Hawaii's statute has explicitly addressed whether the declarant wants or does not want tube feeding. Patients should, therefore, have an updated declaration.

Tube feeding is a medical treatment, but we contend that all health care treatments, whether regarded as basic supportive care or medical intervention, are subject to a benefit/burden analysis and can be accepted or rejected by an adequately informed patient or surrogate decision-maker.

Withholding Versus Withdrawal of Tube Feeding

Decisions concerning initiation, withholding and withdrawal of life-sustaining enteral nutrition are very difficult to make. There is not always a clear sense of whether to start tube feedings. When the prognosis is not clear and there is evidence to suggest that nutritional support can help a person regain health and function or allow time to recover, the more prudent decision is to initiate a time-limited trial of tube feeding. Tube feeding can be withdrawn when it becomes clear that therapy is not effective, or that the burdens of prolonging life with tube feeding outweigh the benefits,[5] or when the patient's prognosis or wishes have been clarified.

Ethicists and the courts equate the act of withdrawing a treatment with the act of withholding a treatment once the appropriate individuals have reached a decision. If withdrawing a treatment is considered more problematic than withholding one, physicians will withhold treatments when they are uncertain as to their benefit, rather than risk not being able to withdraw the treatment later.[4] This denies many patients potentially beneficial treatments.

Many health care providers believe it is psychologically and emotionally more difficult to withdraw treatment rather than

withholding treatment, and this may be more true with tube feeding than with other life-sustaining treatments. However, for the reasons outlined above, we support the view that there is no significant ethical difference between withholding and withdrawing tube feeding if the essential considerations regarding medical indications and goals, patient preferences, and benefits and burdens are the same.[2]

Benefits Versus Burdens of Tube Feeding

The benefit of enteral feeding is the improvement of the nutritional status of individuals who are unable to tolerate feeding by mouth. Tube feeding may decrease the risk of infection, pressure ulcers, and aspiration pneumonia. The burdens of tube feeding include discomfort from the tube and the need for restraints to prevent dislodging of the tube. The probability of aspiration pneumonia may actually increase for some patients following the initiation of tube feeding. Patients undergoing gastrostomy are at risk of infection, painful insertion sites, wound dehiscence, hemorrhage, prolonged ileus, pyloric obstruction and gastric prolapse. Those undergoing jejunostomy incur the dangers of anesthesia and the risk of diarrhea and associated dehydration. Hospitalization is required for both gastrostomy and jejunostomy and may be a stressful experience for cognitively impaired elderly patients.[6-7] These are the quantitative benefits and burdens. The qualitative benefits and burdens are just as important, if not more so.

Some individuals believe in the sanctity of life itself, and to these individuals the prolongation of life under any circumstances is a benefit. Proponents of sanctity of life may insist that diminished quality of life never justifies the removal of life-sustaining treatment. Most people, however, believe that prolongation of a life of minimal quality is a burden and not a benefit.

The evaluation of quality of life of an individual lacking decision-making capacity must be based on that individual's prior preferences, values and goals of life. The objective evaluation of quality of life, however, may be difficult in that the personal beliefs and values of the surrogate decision maker may interfere. Jonsen et al[2] suggest that broad, if not universal, agreement would be possible on the following descriptions:

a. *Restricted quality of life* is an appropriate description of a situation in which a person suffers from severe deficits of physical or mental health. It is a judgment that might be made by the one who lives the life or by others who observe that person.

b. *Minimal quality of life* is an appropriate description for the situation in which an observer (such as the physician or family member) views a patient whose general physical condition has deteriorated beyond recovery, whose ability to communicate with others is severely restricted, and who appears to suffer discomfort and pain.

c. *Quality of life below minimal* is an appropriate description of the situation in which the patient suffers extreme physical debilitation and complete and irreversible loss of sensory and intellectual activity. It might even be suggested that this state would be better described as having no quality, since the ability for subjective evaluation has presumably been lost by the person in such a condition. This description applies to persons in a persistent vegetative state.

Most of the available literature and key landmark court cases support the withdrawal of tube feedings in patients with persistent vegetative state or permanent unconsciousness.[1-3] These cases do not reflect the majority of situations that clinicians face in their daily practices. Elderly individuals with severe irreversible neurological damage such as those with severe dementia and stroke are much more common.[8] These are the kinds of patients with a quality of life considered minimal by the description suggested above. Advance directives are valuable in situations such as these because they select out those patients who consider such a life burdensome and would not choose to be in such a condition.[9-11]

Many patients also consider the burden they will impose on their caregivers. Although some ethicists think this consideration is not appropriate, other individuals believe any burdens a patient wishes to consider are appropriate, and the concerns elderly patients have for their family members should not be minimized by physicians.[4] Tube feeding may necessitate institutional placement. To some individuals life in a long-term-care facility may represent a burden.

Prolongation of life with tube feeding also poses a burden to society. While the cost of medical services and the allocation of resources must never be allowed to intrude into medical decision-making for an individual patient, the cost to society in general is very real. As of 1988, there were an estimated 280,000 Americans in long-term care institutions on tube feeding.[7] In 1989, the number of persons who were 65 years and older was 31 million, or 12.5% of the population. In 2030, there will be 65.5 million elderly persons in the United States, or 22% of the population.[12] Dementia is the most prevalent diagnosis in long-term care facilities. There is already a shortage of beds and personnel needed to care for patients requiring long-term care. Chronic tube feeding in patients with severe dementia and other forms of severe irreversible neurological damage increases the need for skilled nursing services for this population of patients. If public policy does not support the withholding and withdrawal of life-prolonging tube feedings as requested by informed surrogate decision-makers, then the public needs to plan to provide and pay for the additional services that will be required.[7] It is interesting to note that many British physicians do not use feeding tubes on long-term care wards and are reluctant to insert them in patients who are unable to give consent to placement.[13]

The Decision-Making Process

Both legal and ethical consensus support that an adult patient who has decision-making capacity and is appropriately informed has the right to refuse all forms of medical treatment including life-sustaining treatment. An adult patient who no longer has decision-making capacity should continue to have the right to refuse all forms of medical therapy. In order of priority, decisions should be based on advance directives, substituted judgments, and the best interests of the patient.[14-15]

Decision-making capacity refers to a patient's ability to make an informed decision as assessed by health care professionals. Persons whose cognitive ability is not normal should not be disqualified as decision-makers. For example a patient may not be fully oriented to time and place, but still understands the medical issues before him or her. The central test of competence is the evidence that a person understands the nature of the issue and the consequence of the choice he or she is making. It is also helpful to place any choice in the context of a person's own life history and values and ask whether the particular choice is

consistent with these. This is sometimes called the "authenticity" of the choice.[2] A third element of decision-making capacity is the ability to communicate meaningfully.[15] We also find consistent responses over time to be helpful in determining decision-making capacity. A patient may have decision-making capacity for certain issues and not for others. Decision-making capacity should be assessed in relation to the decision at hand.

Advance treatment directives are useful in patients who no longer have decision-making capacity: Natural Death Acts, durable powers of attorney for health care, and living wills.[2] Natural Death Acts are statutes passed by state legislatures affirming a person's right to make decisions regarding terminal care and provide direction about how that right can be effected after the loss of decision-making capacity. They typically contain a model (sometimes mandatory) document.

Durable powers of attorney for health care or health care surrogate is also a statute passed by a state legislature. It authorizes an individual to appoint another person who is familiar with his or her preferences and values to act as the agent to make health care decisions after he or she becomes incapacitated.

Living wills are advance directives communicated by a person to physicians, family and friends in a less formal, less legalistic fashion. Prepared living wills are available, or patients can choose to compose their own form of the living will. In some states, these personal documents are given legal standing. Even if there is no explicit legal recognition of personal documents, physicians can act on them as expressions of their patient's preferences.

Hawaii's statute, "Medical Treatment Decisions" (Chapter 327-D), appears to be a form of a Natural Death Act and seems to imply legal recognition of living wills, either *written or documented verbal statements to a physician.* We believe that a couple of points need to be made regarding Hawaii's Medical Treatment Decisions statute. First, after careful reading, the definition of terminal illness is nonsensical. *Terminal illness* is defined as "any incurable or irreversible disease, injury, or condition which ...will... serve to delay the moment of death of a patient." Second, Hawaii's statute applies to non-terminally ill as well as terminally ill patients. The sample declaration states, "If I should develop a terminal condition or a permanent loss of the ability to communicate...I do not want to have my life prolonged." The definition of permanent loss of ability to communicate includes not only patients who are permanently unconscious, but patients with severe neurological or brain damage, with no reasonable expectation of regaining this capacity. Withholding or withdrawing tube feedings in these cases is sometimes contested by families or professionals. There have been situations in which patient surrogates have contested that patients never fully understood the implications of the declaration. For these reasons, physicians and patients need to document clearly that this is the actual intent of an executed declaration.

Hawaii also has a Uniform Durable Power of Attorney Act (Chapter 551D) which defines durable power of attorney for health care decisions. The attorney-in-fact is able to make decisions about life-prolonging procedures for patients who develop a terminal condition or a permanent loss of the ability to communicate concerning medical treatment decisions with no reasonable chance of regaining the ability. This statute states that the durable power of attorney for health care does not grant the authority to withhold or withdraw life-prolonging treatment unless explicitly stated. This statute is restrictive, and it is proposed that a statute that explicitly grants an attorney in fact authority to make all health care decisions would be more useful.

In the absence of advance directives, the right to refuse medical therapy is exercised on the patient's behalf by an appropriate surrogate decision-maker. Physicians have traditionally turned to the patient's family for consent to provide or terminate treatment, but the legal status of the family to give consent is not always clear. Surrogate decision-making by family members is authorized by statute or case law in approximately half the states. In Hawaii, such a statute has been proposed but has not yet been legislated. In the absence of a family consent statute, a physician justifiably might be uneasy about relying on the authority of the family when making treatment decisions. However, most courts have declined to require judicial intervention as a prerequisite to withdrawal of life-sustaining treatment from an incompetent adult.[16]

With the assistance and advice of a physician, the surrogate decision-maker is asked to make a decision on behalf of the patient, judging as best as he or she can what the patient would have wanted. This judgment is based on the patient's previously stated preferences, values and goals in life. This process is known as substituted judgment.[4,14]

When no information about the patient's prior wishes, values and goals of life are available, the surrogate decision-maker must decide on the basis of what he or she believes is in the best interests of the patient. Determining the best interest of the patient is based on weighing the benefits for the patient of starting or continuing a certain life-sustaining therapy against its burdens on the patient. When there are conflicts, hospital ethics committees can provide assistance. The courts usually are not involved unless there are conflicts that otherwise cannot be resolved.[14]

Cases

The following cases represent hypothetical patients based on true clinical experiences. These cases illustrate and expand on some of the points presented.

Case 1

Mrs A was treated with gastrostomy tube-feeding following a right intracerebral hemorrhage manifested by left hemiparesis, dysphasia and dysphagia. She was incontinent of bowel and bladder, nonambulatory, and required assistance for transfers and all activities of daily living. She had been residing in a skilled nursing facility for two years when she began to point to the tube feeding bottle, then to herself, and then straight upward. She did this repeatedly over a period of time. This was interpreted by her husband as a request to discontinue tube feeding and allow her to "go to heaven." She was evaluated by her physician who witnessed these gestures. A nurse indicated that Mrs A was able to consistently answer yes-no questions by using head shakes and hand squeezes. It was agreed that she understood that death would ensue if tube feeding were withdrawn. Furthermore, Mrs A had a living will indicating that she would not want tube feeding in the event that she had a terminal illness or permanent inability to communicate.

This case illustrates that a person whose communication and cognition are not normal should not be disqualified as a decision-maker. It also shows that communication needs to be

facilitated if necessary. If Mrs A is judged to have the capacity to make an informed decision by health care professionals involved in her care, then she has the right to refuse all forms of medical treatment including life-sustaining tube feeding. The right to refusal applies equally to withholding and withdrawing treatment, and this right is based on the ethical principal of autonomy and the common law right of self-determination. Goldstein and Fuller[4] propose the following guidelines in interpreting nonverbal behavior: 1) Look for consistent responses over time; 2) attempt to verify your interpretation of the behavior with people who know the patient well; and 3) analyze your own reactions to the behavior, and attempt to minimize the projection of your own wishes to the patient. The advance directive, although not applicable at this time, shows that beliefs are consistent over time.

Case 2

Mr B underwent excision of a meningioma. Following surgery he remained lethargic and confused. Verbalizations were sparse and unintelligible. Mr B had a living will that indicated he did not want his life prolonged by tube feeding if he had a terminal condition or permanent loss of ability to communicate concerning medical treatment decisions. He also had a durable power of attorney for health care. He had clearly stated to this individual that he did not want to be "put out to pasture" in a nursing home and that he did not want to be maintained on tube feedings as his wife had been. Following a discussion, the patient's family, including his attorney-in-fact, elected to observe how Mr B would recover from his surgery over the ensuing months and gastrostomy tube feedings were initiated. Mr B failed to improve and he was transferred to a skilled nursing facility. Neurology and neurosurgical reevaluations were requested. A CT scan did not show hydrocephalus and EEG did not demonstrate any seizure activity; there was bilateral slowing. Tagamet and Dilantin were discontinued. Mr B became slightly more arousable but all verbalizations remained unintelligible. Mr B's attorney-in-fact asked that tube feeding be discontinued.

This case demonstrates the use of a time-limited trial of tube feeding may be preferable to withholding treatment when prognosis is not clear. Tube feeding can be withdrawn when the prognosis for recovery is clarified. It also illustrates the need to optimize the patient's medical condition when assessing decision-making capacity, ie, hydrocephalus and seizure activity were ruled out and medications were adjusted. The most important point illustrated by this case is the significance of advance directives in facilitating and guiding medical decision-making involving an incapacitated patient. This patient had a written declaration and a durable power of attorney for health care and had made clear verbal statements regarding his wishes.

Case 3

Mr C, a 60-year-old, had a cardiac arrest. Cardiopulmonary resuscitation was initiated immediately and continued for more than 2 hours. At the time resuscitation efforts were discontinued, Mr C had a spontaneous pulse. He was unresponsive and was believed to have hypoxic encephalopathy. Tube feedings were initiated shortly after his admission to the hospital. An EEG done initially and repeated 1 month later demonstrated no clear cortical activity. Based on clinical findings, a diagnosis of persistent vegetative state was made. There was no recovery over the next 3 months and Mr C's wife and children asked that tube feeding be discontinued.

This case serves as a point of discussion about withdrawal of tube feeding in patients in persistent vegetative state (PVS). The American Medical Association's council report on "Persistent Vegetative State and the Decision to Withdraw or Withhold Life Support" provides a definition, clinical criteria, and differential diagnosis of PVS.[17] This report also offers guidelines in determining prognosis in patients in PVS. For example, of prognostic relevance in this case is that few if any patients who remain vegetative following cardiac arrest recover after 1 month and essentially none will regain cognition after 3 months. Furthermore, prognosis for cognitive return is poor in patients over 40 years old when compared to those younger than 40.

There is an emerging ethical and legal consensus supporting the withdrawal of life-sustaining treatment including tube feeding in patients in PVS. It is the opinion of Jonsen et al[2] that physicians are acting within the law, as currently understood, when they decide to withhold or withdraw life-supporting interventions, unless there is specific law to the contrary in any particular jurisdiction. The conditions required for this decision are: 1) It is virtually certain that further medical intervention will not attain any of the goals of medicine other than sustaining organic life; 2) the preferences of the patient are not known to be contrary and cannot be expressed; 3) quality of life clearly falls below minimal; and 4) family and members of the staff are in accord. They suggest institutions should request their legal counsels to prepare clear instructions for the medical staff in view of prevailing local law. Other than advance directives, Hawaii does not have statutes that specifically address the withdrawal of life-sustaining treatments in a patient in PVS. The AMA's council report similarly indicates that once a diagnosis of permanent unconsciousness has been made, decisions to withhold or withdraw life-prolonging medical treatment ordinarily can be implemented without resorting to the courts. Although judicial intervention has been sought for a variety of reasons by a variety of parties, it is appropriate only when there is a dispute among family members or other guardians about the patient's wishes or interest or among the physicians regarding the diagnosis.

Case 4

Mrs D is 85 years old and resides in a nursing facility. She has had a diagnosis of Alzheimer's disease for 8 years. At this time, dementia is severe. Speech is limited to a few words. She no longer is able to walk, is confined to a bed or chair, and is dependent in all activities of daily living. Mrs D does not recognize or interact in any meaningful way with family members or nursing staff. Supplemental tube feedings were initiated at an earlier stage of her disease. She is not able to swallow and requires total enteral nutrition. Based on what Mrs D had valued in life, her husband and children indicate that she would not want to live in this manner. They request that tube feedings be discontinued. Mrs D does not have advance directives.

Case 5

Mr E is a 78-year old who was admitted to the hospital with an

extensive left middle cerebral artery stroke with right hemiplegia and global aphasia. Tube feeding was initiated shortly after admission. Stroke rehabilitation was initiated but Mr E failed to make any gains in physical, occupational or speech therapy because of lethargy. Over the next several months, there was no improvement in neurological function. He remained dependent in mobility and activities of daily living, incontinent of bowel and bladder. He also continued to be lethargic and aphasic. There was no evidence of a reversible cause of his altered mental status. Mr E's daughter stated that her father would not want to live this way based on his previously stated preferences and beliefs and his joys in life. She requested that tube feeding be discontinued. There were no written or documented verbal advanced directives.

Although a degenerative disease such as Alzheimer's disease or stroke can result in PVS, Mrs D and Mr E are clearly not in PVS. These cases reflect the types of situations that clinicians face in their practices. Based on the preferences, beliefs, values, and goals of life of these patients, their surrogate decision-makers claim they would regard their current quality of life as minimal and burdensome. Cases 4 and 5 are offered to illustrate the need for a clear family consent statute.

Summary

The majority ethical and legal position at this time is to regard tube feeding as medical treatment and the act of withholding and withdrawal of treatment as equivalent. An informed adult patient with decision-making capacity has the right to refuse all medical treatment including life-sustaining treatment and this right is based on the principles of autonomy and self-determination. Advance directives extend this autonomy and significantly facilitate and guide end-of-life decisions of incapacitated patients. Only 8% to 15% of Americans have written advance directives.[18] We believe physicians need to be knowledgeable about the local statutes pertaining to medical treatment decisions and that it is their responsibility to assure their patients have explicit advance directives in the form of written declarations and/or documentation of clearly expressed verbal statements. In the absence of advance directives, an informed surrogate decision-maker should have the right to refuse medical treatment on the patient's behalf and statutes are needed to clarify the role of surrogate decision-makers. Finally, discussions of the ethical and legal issues regarding the withdrawal of tube feeding in patients with severe irreversible neurological impairment with minimal quality of life are needed.

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